ALERT

THE UNIVERSAL FELLOWSHIP OF METROPOLITAN COMMUNITY CHURCHES

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

WHAT IS NEEDED FROM CAREGIVERS? CREATING HOPE

MARCH & APRIL, 1990
Editor: Rev. A. Stephen Pieters

(Report To The National Commission on AIDS, By - Rev. A. Stephen Pieters)

I'm one of the lucky ones. I am a long-term survivor of AIDS. I first got sick with HIV infection in 1982, (although then is was called Pre-AIDS) and was diagnosed with Kaposi's Sarcoma, Lymphoma, and full-blown AIDS in 1984. I was on a government-sponsored experimental drug called Suramin in 1985, and my cancers went into complete remission. After I got over the toxic side effects of the drug, which nearly killed me, and did kill others, I have been well now for four years. And I like to point out that this healing, this miracle happened to a proud, self-affirming gay man.

Over the past two years I have traveled to over eighty different cities and towns around this country, and what I constantly find, as I found in my own experience of living through AIDS, is that people with HIV and AIDS are starving for hope. The greatest gifts that a chaplain gave me when I was told I would not live to see 1985 was a sense of hope. Therefore, out of my own experience with AIDS, I see a primary task for spiritual and religious caregivers as creating hope in the face of HIV.

Unfortunately, I have seen many caregivers who were not willing to offer hope, out of some sort of fear of creating "false hope" for persons with HIV and AIDS. I like to ask, which is better, false hope or false despair? And what is false hope, anyway? If a person is diagnosed with HIV or AIDS, who is to say that he or she won't be among the long-term survivors of this illness? And believing in the possibility of survival and quality life is the first big step in achieving it. Therefore, I would suggest that it is not creating false hope to tell a newly-diagnosed person about the possibility of long-term survival and quality life.

Hope happens when there is something to look forward to, and when persons feel there is something they can do for themselves.

Hope, for someone who is newly diagnosed as HIV+ or as having AIDS, means believing that there is much that can be done to prolong life with HIV, as well as believing that one can enjoy a quality life while living with HIV. Indeed, with advances in medical treatments, as well as the increasing numbers of long-term survivors who are willing to share their experiences, strength, and hope, there is every reason to believe that one can learn to live with this virus, as I have.

But this implies protection for our jobs and housing, and our basic civil rights, as well as equal access to, and guarantee of, quality medical care. I recently lectured in England and Ireland, and found quite a bit of contempt for the United States, because we fail to guarantee medical care for all our citizens. I was told repeatedly that this puts the US on the same level as South Africa.

Creating hope for people who are dying, and people who are grieving, is a more challenging and formidable task. But every faith system that I am aware of has something to offer about hope in the face of death. Whenever I have led a brainstorming session among caregivers on this topic, we have always found a number of ways of creating hope, even in these apparently hopeless situations. Sometimes creating hope simply means bringing a presence of love and compassion to the bedside of the dying, and to the bereaved.

I have discovered as a long-term survivor with AIDS, and as a caregiver, that hope is essential to life; it is imperative to creating quality of life; and it is even theologically correct. I know that one of the distinguished members of the National Commission on AIDS, Eunice Diaz, has understood this for a long time. When I was sick, she visited me, and she fed me, and she nurtured my spirit, and she gave me hope.

What is needed from caregivers? I am reminded of a Native American saying, "The quality of life is not measured by the length of life, but by the fullness with which we enter into each present moment." I believe that in each present moment of the HIV epidemic, All caregivers are called to create hope for persons with HIV and AIDS, regardless of their demographics or their resources. As a person who has lived with HIV since at least 1982, in this present moment I remain absolutely convinced that there is nothing in this life, not even AIDS, not even grief, not even death, that can separate us from the love of God.

MCC LEADS INTERFAITH SERVICE IN ROCHESTER

(Edited by: Rev. Dr. A. Stephen Pieters)

The Rev. Cathy Elliott, Pastor of Open Arms MCC in Rochester, NY, organized and led the Third Annual AIDS Interfaith Vigil of Prayer Service on February 17, 1990 at the Genesee Baptist Church in Rochester.

The service was sponsored by Open Arms MCC in cooperation with GRAIN, Greater Rochester AIDS Interfaith Network. Service participants included leaders of the Iglesia Mahanaim, the Religious Society of Friends, Temple B'rith Kodesh, the Zen Center, Mending Hearts (A Bereavement Group), the Disciples of Christ, the Genesee Baptist Church, the President of the Islamic Center, the Yoga Society of Rochester, the Unitarian Universalists, the Reformed Church in America, Temple Beth Am, Colgate Rochester Divinity School, and St. Mary's Church of the Deaf. Music was provided by the Rochester Gay Men's Chorus, the Disciples of Christ Voices of Peace Youth Choir, the Zen Buddhist Chanters, and a soloist from Iglesia Mahanaim.

The service included a litany of gathering which affirmed faith and hope, and prayer for empowerment for life's journeys. Readings from many different traditions led to a faith reflection by long-term survivor, Rev. Dr. Stephen Pieters. Prayers were offered through chanting by members of the Zen Center.

The Rochester Democrat-Chronicle featured the Interfaith AIDS service the day before and the day after the event. Rev. Pieters, who has attended similar interfaith services across the country reported, "This was one of the most diverse, inclusive and affecting Interfaith services I have witnessed. Open Arms MCC is a small church, with a small budget; and yet Rev. Elliott and the Planning Team Members from GRAIN made a profound difference in AIDS awareness for the Greater Rochester area through this service."

A PLACE OF HOPE AND HEALING

Mending Hearts, a support group which strives to be "a place of hope and healing for those who have lost a loved one to AIDS," is an example of how people directly affected by AIDS are taking the initiative to see that they have the support and help they need.

Two persons in Rochester, NY, who lost lovers to AIDS, began the group because of feeling there was nowhere to go to get the kind of support they needed. The group seeks to "comfort each other in our common experience of profound personal loss. We welcome family, friends, and companions of persons who have died of AIDS."

The group meets weekly, on a Wednesday evening, focusing on the grief process in order to "recover from the loss in an atmosphere of empathy and compassion." The group relies on social and spiritual aspects of group interaction. Mending Hearts has no political or religious affiliation; it is self-governing, and there are no dues or fees for membership. Literature on grieving and AIDS-related bereavement is available free to group participants.

In a pamphlet describing the group, five points about grief are stressed: "Grief is a journey; grief takes a long time; grief is hard work; grief is a roller-coaster of emotions; and grief is painful."

For further information, write Jim or Patti at 61 Alberta Drive, Penfield, NY 14526.

UFMCC AIDS CONFERENCE

Sixty-five persons from around the U.S., Canada, and England attended the Second UFMCC Samaritan College AIDS Conference at the Adams Mark Hotel in Houston, TX, January 19-21, 1990.

Conference participants were uniformly enthusiastic about most of the presenters and content of the conference. People were particularly excited about the Medical Update, delivered by Alexandria M. Levine, M.D. from the University of Southern California Medical School. Many people reported that it was the first time they understood AIDS medically and why it is such a challenge for the medical world.

Friday night, Rev. Ron Russell-Coons, a long term survivor of AIDS, preached a challenging sermon that highlighted a worship service full of challenge and inspiration. Rev. Emmett Watkins, also a long term survivor of AIDS, celebrated Communion, moving many to tears with his affecting liturgy. Saturday night, Rev. Elder Jeri Ann Harvey worked her magic through her preaching, and led a healing service which blessed all who attended.

The next UFMCC Samaritan AIDS Conference will focus on AIDS and People of Color. UFMCC's Department of People of Color will work with UFMCC AIDS ministry to see that a full curriculum is offered in addition to the opportunity to network and worship God. The conference is scheduled for Martin Luther King, Jr., Weekend in January, 1991, in Orlando, Florida. Watch ALERT for further information.

SAN FRANCISCO AIDS FOUNDATION AND LOCAL BUSINESS LEADERS ENDORSE IMPACT AID FOR AIDS DISASTER AREAS ACROSS THE COUNTRY

The San Francisco AIDS Foundation and local business leaders recently announced their support for Senator Ted Kennedy's Comprehensive AIDS Relief Expansion Act, (CARE).

Passage of CARE, also known as impact aid or disaster relief, would expand funding for community-based HIV and AIDS-related services. Most importantly, CARE would mandate a proportional distribution of funds to the HIV natural disaster areas which are the epicenters of the disease.

"By 1993, in San Francisco's gay and bisexual male community alone, one in four men will be diagnosed with AIDS and San Francisco's AIDS-related costs will surpass $400 million," said Pat Christen, executive director of the AIDS Foundation.

"At the Foundation, nearly 80 cents of every dollar we receive comes from individual and corporate contributions," Christen continued, "San Francisco has the highest 'AIDS impact ratio' -- number of new cases to overall population -- in the country. Clearly, the San Francisco community does not have the resources to meet the needs presented by the natural disaster of HIV disease."

"Corporations and individuals have always generously heeded the call for disaster relief in their communities," noted Lee Smith, President of Levi Strauss, International, "It is the combination of Federal relief with these local community contributions that stop human suffering and rebuild communities after a disaster."

"AIDS is a natural disaster of staggering proportions across the country and some communities have been hit much harder than others. San Francisco is one of these communities and we need Disaster Relief for HIV/AIDS as much as we needed disaster relief for the October earthquake. Without Federal relief, this disaster will overrun all of San Francisco's services and devastate our city," Christen concluded, "The time has come for the federal government to respond intelligently."

Please write you Senator or Representative. You can use the following sample letter:

Your name
Address
City, State, Zip

Honorable_____
Building name and #
Washington, DC 20510

Date

Dear Senator or Representative _____:

The Comprehensive AIDS Resources Emergency Act, (CARE), must be approved by Congress as swiftly as possible.

America's cities live daily with the ever-growing HIV/AIDS disaster. Without immediate funding in HIV/AIDS disaster areas our cities' hospitals, AIDS service organizations, community health centers, and other health and support care providers will be wholly overrun.

To date, more than 70,000 Americans have been killed by AIDS -- more than the number of those who were killed in Viet Nam. In the next year and a half, the number of people diagnosed with AIDS will more than double and AIDS will become the leading cause of death for young adults 25 to 44 years of age. Clearly, when one AIDS case is diagnosed every six minutes and one AIDS death occurs every 11 minutes, immediate action is necessary.

I urge you to support Senators Kennedy and Hatch's CARE and move for immediate appropriations.

Thank you.

Sincerely,
Your Name

WHAT'S HAPPENING AT U.S. IMMIGRATION

(Inside the Washington Lobby, Vol 2, No. 5; by Feldblum & Markowitz)

When the news reports a crisis or an event grabs the attention of Congress, lobbyists use the immediacy of the situation to move bigger issues forward. The immigration situation is a perfect example of how this is done. It is also a good example of how lobbyists couple issues together in order to gain momentum for stickier issues.

Two major international conferences on AIDS are scheduled to take place in the United States this summer. Recent national and international news stories report that some international groups are calling for a boycott of the conferences because of the U.S. policy of not granting tourist visas to visitors with HIV infection.

From our standpoint, there are two problems with U.S. immigration policy as it relates to HIV infected people:

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(U.S. Immigration; Cont'd)

One affects foreigners who want to visit the U.S.; the second affects immigrants who are applying for permanent residency. Because of a Helms amendment to the appropriations bill two years ago, HIV infection was added to the INS list of excludable diseases. INS officials can therefore ask foreigners applying for a visa to enter the U.S. whether they are HIV infected and deny them entry.

Last summer, when Dutch visitor Hans Paul Veerhoef came to the U.S. to attend the National Gay and Lesbian Health Conference, he admitted that he was HIV infected and was detained by INS officials. Veerhoef was ultimately granted a waiver to enter the U.S. after numerous AIDS and civil rights groups took up his cause. Several things resulted from the Veerhoef incident. After work by the AIDS lobby and statements of concern by Congress (particularly Senator Edward Kennedy), a new INS waiver policy was instituted, stating that a waiver should be granted to anyone coming to the U.S. for 30 days to attend a conference, do business, visit family or get medical treatment.

The Veerhoef case also served to bring the INS's policies on HIV infection into the international news, embarrassing the Justice Department and giving the U.S. a bad image. Ours is one of the few Western countries that has these restrictions for tourists, and in fact the World Health Organization has stated a position against such a policy.

While the INS's slight change of policy was a gain of sorts, it still did not address the problems faced by tourists or visiting friends and lovers who are HIV infected. It also failed to address confidentiality concerns. The visitor, while still in his or her country of origin, has to self-identify him or herself as HIV infected to the consulate officer. The U.S. consul then stamps a marking indicating a waiver into the person's passport. This creates obvious confidentiality problems.

In addition, U.S. immigration policy continues to be a dire problem for immigrants applying for permanent residency. Current INS policy requires that individuals applying for permanent resident status show a negative HIV test. Those who are HIV positive are automatically denied residence status. The only people who can even apply for a waiver are those who have lived here for seven years or more, or those who can prove they are refugees. But those waivers seem to be theoretical--in practice, almost no waivers have been granted. There is no way of knowing how many HIV infected people haven't come forward to get naturalized because they are afraid of being denied residency on the basis of HIV infection.

Last month, the National Commission on AIDS came out with recommendations on both travel and immigration with regard to HIV infection. It recommended that the policy for travelers be changed so that tourists are not asked about their HIV status. For legalization applicants, said the commission, waivers should be liberally granted, and there should be an overall review of whether HIV should even be on the INS list of dangerous and contagious diseases. Since Congress put it on the list, Congress has to be the one to take it off.

Now lobbyists are trying to make sure that the commission's recommendation will not be used simply to address the immediate problem of the upcoming conferences, but also to change the policy for those seeking permanent residence. In mid-January, representatives from various advocacy groups met with top policy officials at the INS to discuss both travel and immigration issues. A legal paper outlining the groups' requests in the area of travel, prepared by the American Foundation for AIDS Research with input from the ACLU and AIDS Action Council, was sent to the policy officials shortly after the meeting on behalf of a range of groups.

The groups requested that applicants not be asked whether they are HIV infected. This echoes INS policy of ten years ago that directed INS officers not to ask applicants if they are gay. Only if INS officials somehow find out that a visitor or immigrant is gay will they take some action. As with HIV infection, gay and lesbian foreigners are legally excludable from the U.S. (another policy that needs to be changed).

The next step will probably be an announcement from various agencies involved (Departments of Justice and State, and the Public Health Service) of changes they will make in the waiver policy to better ensure confidentiality. These changes will help, but it won't get rid of the underlying problem. For that, advocates will ultimately have to turn to Congress.

RESOLUTION ON U.S. VISA AND IMMIGRATION POLICY

December 1989...WHEREAS, policies which govern the medical examination and exclusion of aliens from the U.S. based upon communicable disease should be determined by sound public health policies alone; and

WHEREAS, these policies need a comprehensive and thorough review based only on public health needs, because other considerations, particularly myth, prejudice and social stigmatization, have been historically but inappropriately considered; and

WHEREAS, the U.S. Public Health Service has stated that there is no evidence that the Human Immunodeficiency Virus (HIV) is spread through casual social contact; and

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(Resolution on U.S...Cont'd)

WHEREAS, the World Health Organization (WHO) has concluded that screening of international travelers cannot prevent the introduction or spread of HIV infection; and

WHEREAS, in its June 1988 report, the Presidential Commission on the HIV Epidemic concurred with the WHO that "the screening of international travelers for HIV infection would require an unjustified, immense diversion of resources from other critical programs of education, protection of the blood supply, and care"; and

WHEREAS, current practices, particularly as they relate to HIV infection, are counterproductive, discriminatory and represent a waste of resources which could be better used in other ways; and

WHEREAS, these practices, in particular, threaten the attendance of participants from all over the world at the Sixth International Conference on AIDS scheduled for San Francisco and the XIX International Congress of the World Federation of Hemophilia scheduled for Washington, DC; and

WHEREAS, the promise of global cooperation on important issues of public health is being jeopordized by current U.S. immigration policy; and

WHEREAS, the Department of Justice has extraordinary power and authority to grant waivers or to take such other action as may be in the best interests of the U.S. particularly where modification of such practices would cause no danger to the public health and no increased risk of disease spread;

BE IT RESOLVED, that the National Commission on Acquired Immune Deficiency Syndrome recommends and calls upon the Administration to immediately implement the following:

1) The Department of State, the Department of Justice and the Department of Health and Human Services should conduct a comprehensive review of immigration policies as they regard communicable disease, particularly HIV infection, focusing on public health needs.

2) Nonimmigrants, such as conference participants, should not be questioned regarding their HIV status as a condition for entry into the U.S. or for issuance of a visa. Similarly, persons carrying medications or products associated with HIV infection or hemophilia should not be subject to detention or questioning.

3) The following practices should also be implemented pending the comprehensive overall review of immigration policies recommended above:

a) For applicants who otherwise qualify for legalization, asylum, or refugee status and who may be infected with HIV, standards for waivers should be liberally applied and they should be routinely granted particularly where family unity, humanitarian and or public interest grounds may exist.

b) For applicants who otherwise qualify for permanent residency and who may be infected with HIV, similar waiver procedures should be adopted to the extent permitted by law.

c) The Department of State, the Department of Health and Human Services and the Immigration and Naturalization Service should engage in cooperative efforts to institute policies and disseminate information targeted at notifying relevant alien groups of the availability of waivers and the circumstances under which they are granted.

d) To the extent that HIV testing is part of any medical examination of applicants for permanent residency refugee status or legalization, the Immigration and Naturalization Service and the Centers for Disease Control should carefully monitor training and compliance with their Instructions to Designated Physicians. Particular attention should be paid to pre- and post-test counselling, confidentiality and appropriate referrals of persons for medical care and follow-up counselling.

e) Confidentiality should be protected where HIV testing is part of the medical examination of applicants for visas, permanent residency, asylum, refugee status or legalization. Permanent markings in passports (including the use of codes which may become known) which in any way suggest that a person is infected with HIV or any other designated communicable disease should be prohibited. Where medical examinations take place, steps should be taken to safeguard all medical information (including HIV status), particularly from staff recruited locally in foreign countries.

SCABIES INCREASING, DIAGNOSIS OFTEN MISSED

(By John S. James, Aids Treatment News; Issue #98, Mar 2, 1990)

Marcus Conant, M.D., a dermatologist and a leading AIDS expert in San Francisco, alerted patients at his February monthly public meeting that he has seen a major increase in scabies in the last few months, with 20 cases since Christmas. Scabies is caused by a mite, a small spider which burrows into the skin. It is very contagious, often transmitted by sexual contact, and often particularly severe in persons with immune deficiencies.

Scabies is not difficult to treat. The biggest problem is getting it diagnosed, as physicians often do not look for it. Historically, scabies becomes widespread periodically clearly a major increase is starting now, at least in San Francisco. (We do not know about other cities.)

Symptoms include severe itching, which may be worse at night. Itching and rash often start in the web between

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(Scabies Increasing...Cont'd)

the fingers. Other areas likely to be affected include the genitals, underarms, elbows, and buttocks. Usually the head is not affected - but it may be in people with immune suppression.

Treatment requires a prescription cream or lotion (such as Kwell), often applied everywhere from the neck down and left on overnight, then washed off in the morning, for four successive nights. Instructions must be followed carefully; sometimes, for example, physicians forget to tell patients not to wash their hands at night, after they have applied the medication. The mites are often found on the hands, and they can survive there and re-infect the rest of the body if the hands are not treated.

In addition, clothing and bedding must be collected and properly cleaned, and all sexual contacts must be treated simultaneously, to avoid reinfection.

AIDS AND THE FAMILY SEEN FROM A CAREGIVER'S EYES

(By Carol Richer, Ottawa, Ontario)

Having lived the situation for the past two years of being a caregiver for my spouse, I would like to share some of the dynamics of my experience. I would like to discuss these by speaking about the person with AIDS, the main caregiver and the extended family and friends.

I have been in a monogamous relationship for the past six years with Ron. Three-and-a-half years ago, Ron began feeling some unusual fatigue and experiencing frequent infections, which led to more investigations from the family physician and several specialists. A diagnosis was made which required the knowledge of Ron's HIV status. The result of the HIV testing came back positive, and we were told that because he had a very low T4 count he could expect to get very sick in the next six months (i.e. pneumocystis carinii, other opportunistic infections, etc.)

As a couple, this was a big shock. We now had to deal in terms of a chronic disease. This disease altered the social, psychological and financial aspects of our lives and also the way we related to each other. It meant trying to adjust in a world which had suddenly, seemingly come to a halt. We had to examine different facets of our beings, i.e. our relationship, our attitudes together and individually, our communication skills, our feelings and our day-to-day planning.

Dealing with this situation has changed my life completely. I would like to talk about some different aspects of my experience.

PERSON WITH AIDS: How is that person dealing with the diagnosis? What was his or her attitude towards life, and what was it before this diagnosis? Was that person able to communicate well before the HIV positive diagnosis with their significant other, friend or family members? Was that person able to share his or her feelings before? What is the situation now? Was that person able to deal well with life's realities before, and how are they dealing at this time? Is he or she able to maintain hope in the face of life's different situations including what is happening at this time?

MAIN CAREGIVER: The main caregiver is either a spouse, a close friend, a parent, a brother or a sister; it is somebody who cares so much as to decide to share this journey with the other person. I insist on the word "decide" because we all have choices. (I remember once Ron asking me to make the decision as to being there with him, helping him, or choosing to leave him is I needed to.) This to me is the first step of joyfully accepting this specific challenge or journey. The main caregiver has to look into his or her relationship with the person with AIDS, his or her own attitude towards life in general, his or her communication skills, his or her feelings in general, and towards this given situation of life. This person also has to learn to adapt to everyday changes and challenges.

EXTENDED FAMILY/FRIENDS: To develop this notion, I need to share my own experience. My own situation, having lasted now for the last two years, has helped me sort through the different friends that Ron and I have made over the years. At the beginning, people seemed to be very attentive to our needs, and seemed to be well intentioned as far as helping, often saying things like, "if you need help, please call". I quickly realized that this response is one that is much easier to say for people than for them to act on. It is easier to deal with people who say things like, "I have two or three hours to spare this evening", or "I will bring dinner for you", or "I will come and clean windows or mow the lawn for you". As time passed, I realized that, for a good number of people, it is easier to forget what is happening than it is to act on the situation. I sincerely think that it is human nature to put something aside because in dealing with difficult situations, one can perhaps make them go away from his or her mind if one can put them aside long enough or stop thinking about them.

Ron and I were very involved in the gay community and with the Church which Ron was pastoring. Therefore, we had a lot of acquaintances and friends. At one point, about a year ago, while Ron was in the hospital, I decided to go away for a week for some "me time" to re-examine and re-evaluate my life and my own committment to Ron. Before leaving, I took our personal telephone directory and started drawing up a list of names and phone numbers of people I could count on. This was a very revealing experience. I realized who our friends really were; who I could count on, etc.; by the same token, I

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sensed myself feeling left out by so many. I felt betrayed about the non-commitment from so many individuals. It was an eye opener regarding people's behavior given the situation. It is in fact very hard for many individuals to deal with a chronic health situation - with death and grieving - because it brings one's own death into perspective. Confronted with this type of situation, it is certainly easier to choose not to deal with it and to pretend that nothing is going on.

Family members are also important in this situation. Like friends, they may choose to be involved and loving, or not to deal with the situation at all. In my own experience, it has been interesting to see how both of our families have reacted to our situation. In general, they have responded in a very loving way. One of the main difficulties in this situation is for the caregiver to be able to constantly evaluate what needs to be told to family members. I have had situations (Ron's family are all quite far) where I have had to decide on the importance of letting family members know just how sick he is at a given time, and I have had to evaluate how badly Ron needs to see various family members at times. This interpretation is at times like walking a thin line. I often got the feeling that I was either over-reacting or underestimating their reaction to the seriousness of the situation. Family members often have a hard time dealing with a sibling's death, sexuality and the social pressures etc., because these topics touch a very intimate part of their personal lives.

Now that I have defined the different significant persons in the situation of a caregiver, i.e. the person with AIDS, the main caregiver and the extended family/friends, I would like to discuss different important aspects which are necessarily altered during the course of this given journey as a caregiver. The situations I will discuss in the next sections affect one's life in that the course of this specific disease redefines certain concepts of one's day-to-day life, and disorganizes the feelings accompanied with this mess (I know how harsh this word can be, but it is a very honest one). This life situation or challenge redefines the term relationship, one's attitude in general, the communication between the person with AIDS and others, the feelings (this one being often left aside because of one's inability to deal with deep emotions), everyday goals and expectations, and the multiple problems with health care, financial changes, transportation, to name but a few of the problems.

RELATIONSHIP: The relationship between the caregiver and the person with AIDS will influence the way we deal as caregivers. As I have said previously, the situation brings alterations to the relationship but, basically, the relationship continues in the same line as before the news of the illness. It is therefore very important to try to understand what has been going on before diagnosis and to examine how this affects the future of the relationship.

ATTITUDE: It is very important to understand the effect of attitude on a given situation in life. For my part, it has been very important. Ron is a very optimistic person who always makes the best out of every situation no matter how hopeless it may seem at the time. The caregivers attitude needs to be in line with that of the person with AIDS. By this, I mean that the caregiver needs to be able to adjust with the hopes and distresses felt by the person with AIDS on a day-to-day basis. This is not easy. For example, I feel I am often more realistic than Ron. The two of us together are able to keep things in a positive trend and re-evaluate our hopes and sorrows on a daily or weekly basis.

It is also very important to respect one's attitude toward the illness that they have. For instance, some people, when they become ill, just want to crawl into bed, pull the shades down, and wait for death to come. A seemingly passive approach but this situation needs to be respected. After all, one's decision is very important, and it has to be respected at all cost. The attitude coming from friends and families is also very important because it often influences the person who has AIDS and the primary caregiver. For example, Ron and I have often felt the subtle pressure from friends that say if one has a terminal or chronic illness, one is supposed to suffer and die, especially when one comes close to death on several occasions. It's a given scenario. It's expected. This concept has a strong influence because there are times when we have felt that the next thing to do is wait for death. We have had to fight tooth and nail in order to keep on going in as normal a way as possible. The conclusion we have both come to is that: you are fully alive until the moment you stop breathing. I think that this has been a phrase that has kept us going many times. It has inspired us to appreciate special moments, and to look forward to projects and days ahead. It has given us energy for life's activities and for the sorrows that come with the inevitable grieving of a loved one. It is important to note that grieving is not just something that happens when somebody dies; it happens every time there is a change or some kind of a loss in one's life. One's choices are constantly limited. There is ongoing loss.

COMMUNICATION: It is essential to evaluate how efficiently the caregiver is able to communicate with the person with AIDS. Was there communication before the illness and was it honest in that it helped the persons grow or become closer. Effective communication comes from active listening, response and participation. It is not an easy thing to do; some of the subjects which need to be discussed are often very painful. For example, for Ron and I, one of the most difficult subjects to talk about

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at first was his death. We are just not trained to think in terms of somebody dying at a young age. We grew by talking about his eventual death, and we were able to make arrangements for the future. We were able to come to terms with wills, funeral arrangements, a memorial service, and the meaning of death for both Ron and me. I must say that, through this very basic communication, we were able to change our attitude towards death in that, for some reason or another, it just did not seem as final anymore; we were able to give death meaning and not see it as final as it may have seemed before. This all came from active communication between us. Communication has also made us able to discuss every treatment, our hopes and distresses and plans for the near future. It has made us able to work through anger and sadness, and to cherish the meaning of our relationship.

FEELINGS: This subject has to be one of the most difficult parts of being a caregiver. It's really an emotional roller coaster when dealing with one's own feelings as well as the feelings of the person with AIDS. I found that, for myself, the feelings went from anger, to despair, to sadness, to joy, and back to anger again. I found that I had a hard time grieving, and that my feelings were not always in touch with those of Ron. As time goes on, I find that I have less and less energy, both physically and emotionally, to deal with my feelings and I seem to get depressed very easily when something happens to Ron. I do mind-games with myself. For example, when everything is going well I think that it will continue to go well and, therefore, I forget for a time what the realistic situation is. I have, as caregiver, to constantly remind myself of the reality of the situation. I have to try to remain as positive as possible in the short term and balance that with the long term reality of AIDS.

This brings me to two very important issues that I would like to close with: the everyday "hassles" of the situation and taking care of myself as a caregiver.

By everyday "hassles", I mean dealing with hospital/doctors on a weekly basis. This becomes frustrating and increasingly difficult because we are dealing with so much that is unknown. Therefore, we often feel left out or misinformed on the part of the medical care team. There is often also the fact of dealing with the issues of sexuality which are often unresolved ones for the medical team leaving them not knowing how to cope with a spouse of the same sexuality, and/or friends/family members. I know that at times, I have felt at the mercy of a medical system which seems to provide care without involving the patient and caregiver. By this, I mean that unless the caregiver or the patient specifically and constantly asks for information, nothing is given freely.

I also believe at times that the person with AIDS becomes a "guinea pig" for researchers and that these researchers although well intentioned, do not involve themselves, or have not been involved in situations where they have to be researchers as well as cargivers for individuals who require from them total care in all aspects of their lives. I am sure that they also feel as frustrated as we do. Sometimes there also seems to be a lack of continuity of care with the "team" at the Clinic.

Another "hassle" or problem that arises, is dealing with somebody who cannot work and therefore is in need of financial assistance for medication, lodging, every day necessities, etc. In order to obtain the necessary assistance, a number of forms have to be filled out; one has to tap into the social system and encounter a lot of dead ends from not knowing how to get certain wheels in motion or to deal with bureaucratic institutions that do not seem to realize the gravity of one's health and financial situation. Another aspect which causes a lot of frustration is trying to provide efficient transportation for people with AIDS. They require a lot of assistance getting to and from doctor's offices, clinics, hospitals; this can become a regular part of one's daily routine depending on the person's needs and health situation. All of the above situations culminating with the frustrations and feelings encountered can bring a caregiver down leaving them unable at times to provide the proper support to the person with AIDS.

This brings me to the aspect of SELF-CARE. It is a very broad subject to discuss. I find that I do not have all the answers for this because I often feel guilty for taking care of myself. There is always the feeling that the caregiver is not the one who is sick so, therefore, should not have big problems emotionally. The irony is that I think the caregiver needs a lot of support and help. I personally do not know how this can be provided in all areas. I know that often I have felt like saying: "I need to be taken care of too. I need somebody to hug me and to boost me up. I too have needs."

My only hope would be to share these feelings and needs with others dealing with similar situations to mine in order to tentatively find solutions which might be helpful both in making the situations easier to deal with, and in seeing those same situations as positive to the future. I would also like to add that the role of caregiver, although being a difficult one, is one that puts a person in touch with the "real world". It helps one redefine one's life in re-examining one's value system in life. It also helps a person discern between what is important from what is futile. It lets one know that everyday is worth living at its fullest, and that it is in giving of ourselves to others that we grow and learn the meaning of life in general. I know that I will never be the same as before this experience; something has happened which will alter my life from now on, and this, although painful at times, is a very positive journey.